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University of Washington
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Abstract

Military Families with Chronically Ill Children
A Needs Assessment

Susan D. Morgan, Capt, USAF
1995

Military families with chronically ill children experience not only the stressors of caring for their chronically ill child, but must also contend with the rigors of military life. Stressors involved in caring for a chronically ill child include continuous care demands, marital distress and financial burdens. Stressors of military life include geographic mobility, spousal absence and working within the military system. Many programs utilizing the principles of case management have successfully been implemented within the civilian sector in order to minimize the stressors of families with chronically ill children.

The purpose of this project was to design a Needs Assessment Questionnaire in order to determine the needs military families caring for their chronically ill children experience in providing and obtaining care for their child and to determine if case management services would be helpful in meeting these needs. In order to provide the structural skeleton necessary in developing the questionnaire, a conceptual framework was designed taking the stressors of a family caring for a chronically ill child and combining these with the stressors of military life.

The instrument was found to have both content validity and face validity. Experts were not only asked to verify content validity but were also asked to evaluate the conceptual framework developed. Results and responses indicate further refinement of the conceptual framework is needed. Families were asked to provide comments and suggestions regarding the questionnaire in addition to verifying face validity. These responses and suggestions will be used in revising and improving the Needs Assessment Questionnaire in the future.

Key words: military families, chronic illness, children, needs assessment, content validity, face validity

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Military Families with Chronically Ill Children

A Needs Assessment

by

Susan D. Morgan

A thesis submitted in partial fulfillment
of the requirements for the degree of

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1995

Approved by Patti Brandt
(Chairperson of Supervisory Committee)

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University of Washington

Abstract

Military Families with Chronically Ill Children
A Needs Assessment

by Susan D. Morgan

Chairperson of Supervisory Committee: Professor Patti Brandt
Dept. of Parent Child Nursing

Military families with chronically ill children experience not only the stressors of caring for their chronically ill child, but must also contend with the rigors of military life. Stressors involved in caring for a chronically ill child include continuous care demands, marital distress and financial burdens. Stressors of military life include geographic mobility, spousal absence and working within the military system. Many programs utilizing the principles of case management have successfully been implemented within the civilian sector in order to minimize the stressors of families with chronically ill children. Would the institution of such programs be helpful in diminishing the stressors of military families with chronically ill children?

The purpose of this project was to design a Needs Assessment Questionnaire in order to determine the needs military families caring for their chronically ill children experience in providing and obtaining care for their child and to determine if case management services would be helpful in meeting these needs. In order to provide the structural skeleton necessary in developing the questionnaire, a conceptual framework was designed taking the stressors of a family caring for a chronically ill child and combining these with the stressors of military life. The domains of the questionnaire were formulated by conducting a review of the literature and combining that information with personal observations and experiences gathered in working with military families and their chronically ill children.

After development of the Military Families with Chronically Ill Children - A Needs Assessment Questionnaire was complete, a verification of face validity and content validity was performed. The instrument was found to have both content validity and face validity. Experts were not only asked to verify content validity but were also asked to evaluate the conceptual framework developed. Results and responses indicate further refinement of the conceptual framework is needed. Families were asked to provide comments and suggestions regarding the questionnaire in addition to verifying face validity. These responses and suggestions will be used in revising and improving the Needs Assessment Questionnaire in the future.

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Introduction

Military families with chronically ill children are subjected not only to the stress of caring for their ill children, but they have the added demands of military life. From a review of literature, it is apparent families with chronically ill children have many stressors, including continuous care demands, marital distress, and overwhelming financial burdens, just to name a few. These families have the stress of caring for their child compounded by the rigors of military life, such as geographic mobility, spouse absence, isolation, alienation and the need to obtain resources for the chronically ill child both in the military and civilian sectors.

In order to provide continuity of care to families who exist in an inherently fragmented and socially isolating environment such as the military, programs must be developed to help minimize the demands of military families with chronically ill children. In the civilian sector many successful programs have been implemented using case management to assist families with chronically ill children by diminishing the burdens these families face. Positive outcomes resulting from such programs included parents feeling they were receiving individualized personal attention, comprehensive care for their children , education and support (Weis & Sharpton, 1993). To design programs that specifically address the needs of the targeted population requires a thorough needs assessment and analysis of military families with chronically ill children. This has not been done; thus the need exists to explore military families' life experiences of caring for a chronically ill child.

Purpose Statement

The purpose of this thesis is to determine if the questionnaire designed specifically to identify the needs of military families with chronically ill children contains content validity and face validity. In devising the items for the questionnaire, a review of the literature was performed in order to pinpoint areas of domains related to the targeted population and to be utilized in the construction of the instrument. Unfortunately I was unable to locate any information regarding military families with chronically ill children. Because of this, many of the items included within the questionnaire are based on information obtained through personal observations and experiences gathered while working with these families.

Content Validity

According to Waltz, Strickland & Lenz (1984) content validity determines "...whether or not the items sampled for inclusion in the tool adequately represent the domain of content addressed by the instrument." (p. 141 -142). Research objectives identified to provide the basic structure of the questionnaire were the following: 1) what unique stressors do military families with chronically ill children experience? 2) what are the family's perceived needs in regards to medical support and services provided by the military medical system? 3) is the family receiving adequate and appropriate support from the military community? and 4) would case management services fill these needs? Additionally, the questionnaire development was powered by a conceptual framework which was formulated based on information concerning families with chronically ill

children combined with concepts regarding military families derived from the review of the literature.

Face Validity

Nunnally (1967) states face validity "...concerns the extent to which an instrument " 'looks like' what it is intended to measure." (p. 99) To determined face validity the following questions must be posed to the targeted population, military families with chronically ill children: 1) Does the needs assessment questionnaire address issues which are of concern to military families with chronically ill children? 2) Are the questions clearly written? 3) Are the response sets complete? and 4) Is the information contained within the questionnaire items accurate?

Review of the Literature

Military Families

Military families who care for their chronically ill children have the stress of caring for their chronically ill child compounded with the rigors of military life, such as geographic mobility, spouse absence, isolation, limited social networks and the difficulties of working within the military medical system. Each will be discussed in the following sections.

Geographic Mobility

Military family life is stressful. The military requires the active duty member to relocate every two to three years, and the complexity of moving in the military is tremendous. Geographic mobility does not just involve the physical task of moving, but is emotionally taxing as well (Marsh, 1976). The spouse and children often experience feelings of immense alienation and isolation, for the non-active duty spouses must relinquish their jobs, their friends, and support systems, while the children give up their circle of friends, schools and activities.

Spouse Absence

Another factor that places stress on the military family is the prolonged absence of the active duty spouse. Many active duty members are required to deploy and be absent for periods of up to 18 months, while others must attend schools and camps for months at a time as part of their ongoing military training. The family adjusts to the separation, roles are shifted and the spouse "left behind" becomes the head of the household, entirely

responsible for every activity in the home. As time goes by, the family adapts to the new lifestyle. Reintegration of the family is often difficult as roles are confused and must be renegotiated. The returning spouse, often anxious to resume family responsibilities, may be critical of how their responsibilities were handled during their absence. Surprisingly, for many military families the return of the absent spouse is the most difficult of times related to separation because of the role conflicts and emotional turmoil that ensues (McCubbin & Dahl, 1976).

Working Within the System

Working within the community resources of the military can also be difficult. Military families must be very adept in negotiating the bureaucratic obstacles and quagmire of paperwork required to obtain services and resources.

Chronic Illness

An illness is considered chronic when it "interferes with daily functioning for more than three months a year" (Perrin, 1985, p. 2). The definition of chronic illness integrates many factors, not only the condition. According to Stein, Bauman, Westbrook, Coupey & Henry (1993), a chronic condition "is not limited to illness, impairment, disability, or other abnormal health symptoms or manifestations" (p. 344). It includes the basis of the condition, be it biological, psychological, or cognitive in nature, the duration of the condition, and the sequelae (Stein et al, 1993). In addition, considerations concerning the dependency on medications, diet, technology, and personal needs for assistance are involved in the definition of chronic illness. The characteristics of chronic illness in

childhood include the potential of the illness to impact parents and siblings physically, developmentally and psychologically (Jessop & Stein, 1988). These characteristics are also taken into account when determining if a child's illness is considered chronic. Every family with an ill child is unique, responding differently, adjusting and adapting in their own ways to their individual situation (Davis, 1993) and therefore an illness that negatively impacts one family may not adversely affect another.

Statistically, it is difficult to determine the number of children afflicted with a chronic illness in the United States. It is estimated that approximately 1 million children are affected by a chronic illness (Martinez, Schreiber & Hartman, 1991). Other statistics cite as many as 100,000 children are technology-dependent (Leonard, Brust & Nelson, 1993). The most common chronic diseases of childhood are diabetes (1.8% of the children), asthma (2-5%), congenital heart disease, epilepsy, cerebral palsy, brain injuries, Down's syndrome, leukemia, cancer and cystic fibrosis (Davis, 1993). Increasing numbers of children are now receiving medical care at home. Studies have shown that although home care of the chronically ill child is more cost-effective than continual hospitalization, the psychological and physical toll for the families caring for these children is enormous (Leonard, Brust & Nelson, 1993).

Benefits of Home Care

Numerous benefits have been identified as a result of caring for children at home. These include improvements in the child's physical condition and enhancement of development, both socially and physically. The family as a whole benefits because of increased family cohesion and the return of control in the care of the child to the parents

(Lewis, Alford-Winston, Billy-Kornas & McCaustland, 1992). Most importantly, home care allows the family to act as a unit.

Stressors

Intertwined with the positive effects of home care on the chronically ill child and the family are the negative effects. These include the demands of continuous care, marital distress, lack of adequate support and the financial burdens the families must endure (Lewis et al, 1992). Each will be described individually in the following sections.

Continuous care demands.

Today's advanced medical technology allows many chronically ill children to be cared for at home. These children still require constant care but the care demands shift from the hospital nursing staff to the parents. For the families with ill children that do not require around-the-clock care but still need treatments, therapies, medications, and special diets, an inordinate amount of time is taken from the normal family routines to prepare for and administer these special needs.

Marital distress.

Marital distress is considered to be one of the major consequences of caring for a chronically ill child at home. Marital distress is the result of the increased responsibilities (Leonard, Brust & Nelson, 1993). Parents do not have the time to themselves to communicate and to foster romance through intimacy and affection (Walker, Manion, Cloutier & Johnson, 1992). There is a lack of privacy as a result of the care demands of their ill child and the normal demands of their healthy children. Because of the marital

distress and lack of time, studies have shown parents are less attuned to their other children's needs, often demonstrating less affection and approval (Walker et al, 1992).

Financial burdens.

Not only are parents faced with the care demands of their chronically ill child and the accompanying marital distress, but they also are challenged with the ever increasing financial burdens. These families must be very adept at negotiating reimbursement issues, insurance companies, and third party payers. In addition, many families are financially incapable of or do not qualify for 24 hour nursing care in the home and therefore one parent is required to stay at home to care for their child. This substantially reduces the household income (Walker, Manion & Cloutier, 1992). For families with children that do not require constant care, there are the additional costs of transporting their child to specialty clinics, the costs of special diets and medications, and frequent absences from work related to numerous treatments and hospitalizations for the child (Martinez, Schreiber & Hartman, 1991).

Military Families with Chronically Ill Children

While conducting the literature review, I was unable to locate any information concerning military families with chronically ill children. To aid in the visualization of the stressors associated with military families caring for a chronically ill child, I have developed a framework depicting the factors that come into play not only as a family with a chronically ill child but also as a military family (Figure 1). Because of the lack of literature, the following information regarding military families with chronically ill children and the struggles they face in contending with geographic mobility, spousal absence and working within the system are based on personal experiences and observations of these families. As an active duty military member and as a pediatric nurse, I have worked closely with military families with chronically ill children for many years.

Geographic Mobility

As previously mentioned, moving frequently is very stressful even in the best of circumstances. Moving with a chronically ill child brings even more complexities and emotionally stressful components into the situation. Along with the normal stressors of moving, families with chronically ill children are also concerned with the loss of primary care providers who are familiar with their child's medical history, treatments and care. There is also the fear the services available within the community at their present duty station will not be available or will be difficult to obtain at the future duty station. If the

child requires special treatments and equipment, families must arrange for these services at the new duty station.

Each armed force service has an Exceptional Member Family Program designed to monitor and track all families with members experiencing physical and psychological disabilities or illnesses requiring specialized care. Families are eligible for enrolling in this program if a member of their family has physical, emotional, developmental, or intellectual needs that might limit the individual's capability . One advantage of enrollment in this program is the elimination of the need for the entire family to be transferred overseas as part of the active duty member's military obligations. However, the active duty member may still be required to fulfill a tour overseas unaccompanied by their family, leaving their families behind for up to 18 months at a time.

Military Life + Caring for Chronically Ill Child = Stressors Associated with Military Families Caring for Chronically Ill Child

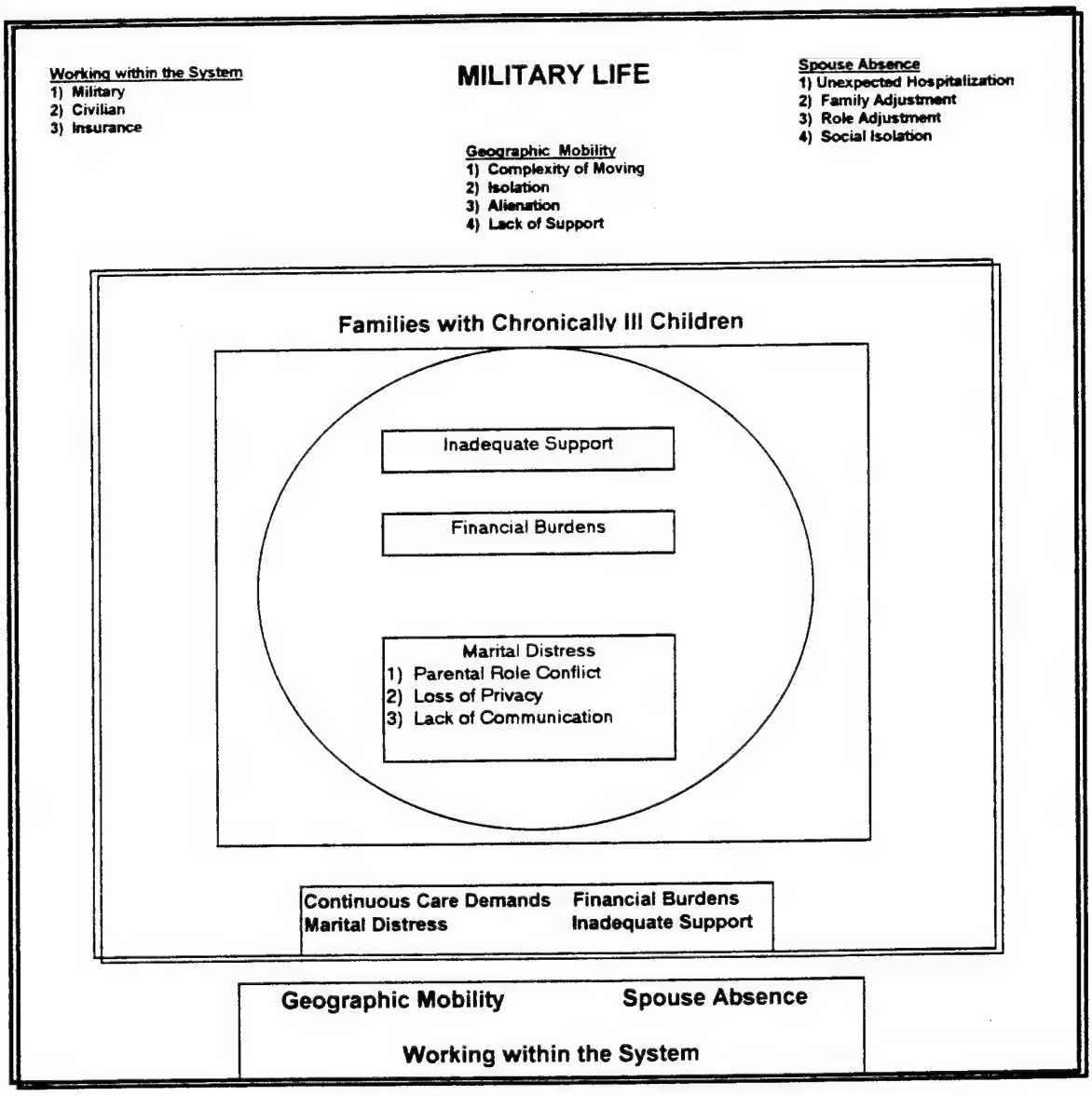


FIGURE 1: Stressors of Caring for a Chronically Ill Child Compounded by Military Life

Spouse Absence

It is understood among all military families they may have to endure a prolonged absence of the active duty member at some point in their military career. Spouse absence, as previously mentioned, can be very trying for the most secure and stable military families. For military families with chronically ill children, the absence can precipitate a crisis. For the spouse that remains at home, there are the added responsibilities of juggling child care, providing care to their chronically ill child without any assistance from the absent spouse, and maintaining the household. As a result of constant relocation most military families are not in close proximity to family and social support networks who might come to their aid during separation. Therefore, family and social support resources are limited or inaccessible.

I have also noted through my years of working closely with these families an unsettling number of unexpected hospitalizations of these children during family separations. On innumerable occasions during the admission process a parent has said " Why does this always seem to happen when his/her father/mother leaves?" I have seen these parents emotionally and physically exhausted trying to stay at the hospital, in addition to caring for their other children and running the household. These parents appear overwhelmed by the obligations and responsibilities placed upon them and are unable to identify and obtain the support and resources required. Parents have said to me "If I could just have someone to sit with my child in the hospital while I go home and take care of some things, this would be much easier".

Working within the System

Because of the structure of the military, there are rules and regulations which must be followed. Unfortunately, during a time of crisis (such as the diagnosis of a child with a chronic illness) these rules and regulations may seem trivial to the parents of the child who has just been diagnosed. There are however, exceptions to the usual rules, such as military policies which allow the active duty parent leave to be with their child during the initial hospitalization and diagnosis. In some cases, inconsistent implementation of this policy is problematic.

Other difficulties are the almost full-time job of completing the required paperwork needed to obtain services for the chronically ill child both in the military sector and in the civilian sector. There are many services available to the military family with a chronically ill child, but only if the family is aware of those services or is in contact with someone familiar with the services. One of the concerns most frequently voiced by parents is the lack of continuity of care provided by the military medical system. Because of the transient nature of the military population, physicians and health care providers maybe required to relocate every two to three years. The necessary transfer of information regarding the medical history, care and treatment of the child may not be completed because of the continual relocation of personnel and families. From my experience, this is very frustrating for parents, as they perceive the medical care received by their child as fragmented.

Case Management

In the civilian health care system, many programs utilizing case management services have been implemented successfully (Martinez et al., 1991; Lewis et al., 1992; Steele, 1993). Case management is designed to ensure the appropriate use of services, continuity of care, quality outcomes and cost-effectiveness (Jackson & Vessey, 1992). Case management services for chronically ill children attend to the physical, developmental and psychosocial needs of the child (Steele, 1993). For comprehensive care, all aspects of the child's life must be considered; of utmost importance is the child's family. According to Lewis et al (1992), the family is a constant in the child's life. Each family is equipped with unique strengths and has individual weaknesses and needs. Case management services recognize the family's needs and strengths, coordinating care and services to promote optimal growth, physically and developmentally of the child in step with the family's ability to provide care and make decisions (Lewis et al, 1992). Jackson & Stein (1992) state case management is the highest form of intervention offered by the primary care provider to chronically ill children and their families and includes service planning, guaranteeing access to services, evaluating services and being the family's advocate in all facets of care.

Recently, "family-centered care" has received a great deal of attention because of the emphasis placed on the family as being a constant in the child's life, whereas "service systems and personnel within those systems will fluctuate" (Desguin et al, 1994). Family-

the medical care of their child. Functioning under this premise, family-centered care takes case management one step further by placing control of the child's care back into the family's hands (Desguin et al, 1994). "...the best health care services for children with special health care needs are family-centered and must take into account the social and community support systems that relates to the family." (Steele, 1993)

Conceptual Framework

In developing the conceptual framework for the needs assessment tool, I have used Brickman's models of helping and coping (1982). These models are based on two principles, blame and control. Blame refers to attribution, specifically the individual, disease or situation that is responsible for the problem. The term control is applied to the individual that is responsible for the solution, and may be the nurse, the patient, or the physician. These models enable an analysis of how the patient is being treated related to the levels of blame and control.

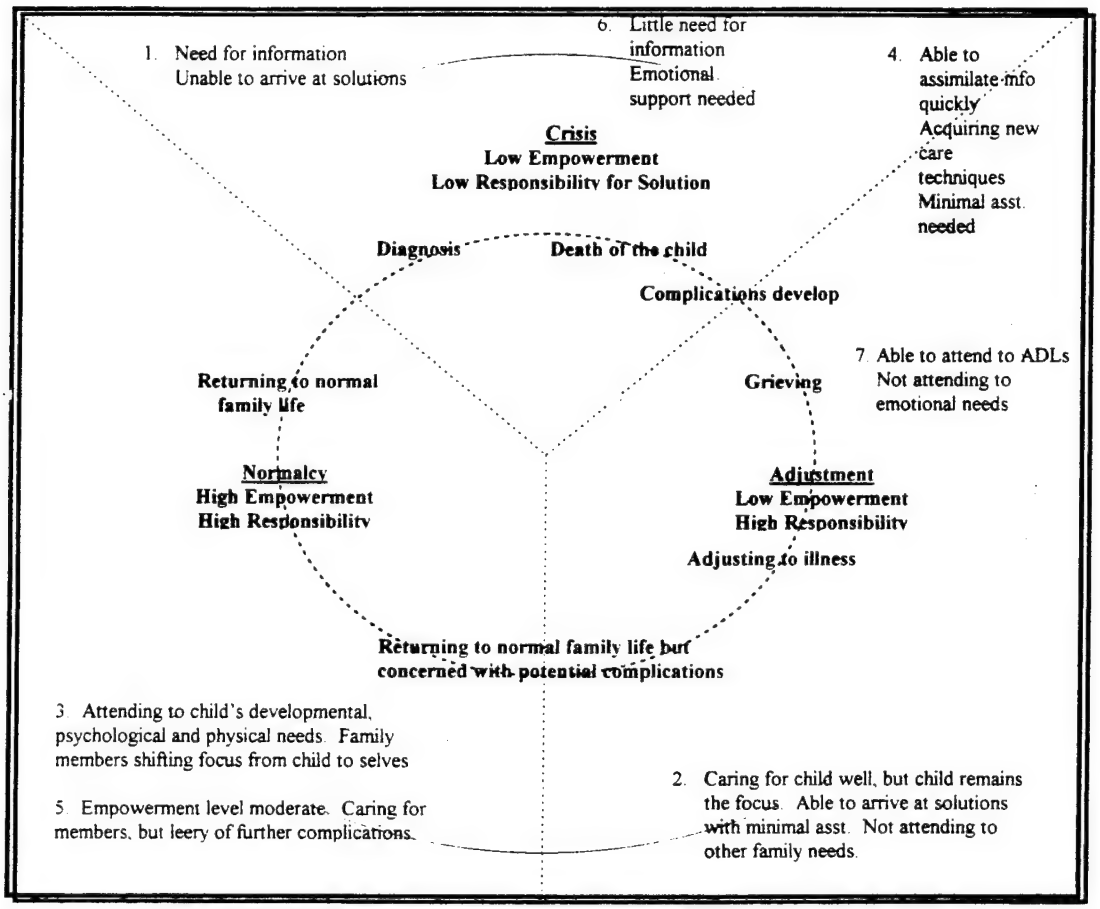
In working with families who have a member with a chronic illness, health professionals are required to become advocates for the families. "Advocacy becomes a process whereby client autonomy in making decisions is guaranteed, while at the same time they are given all the help needed by the professional to make such decisions" (Pace, 1985, p.78). Blame is not a term that can be appropriately applied to families, for chronic illness is not a situation the family has brought upon themselves. According to Boyd-Franklin (1989), blame is counter-productive and negates empowerment. The term blame needs to be replaced with the term of empowerment. Empowerment refers to the power of the people to do whatever is necessary to reach their goal (Saylor, 1992). "Empowerment most often involves helping parents to regain control of their families and feel they can effect important changes.." (Boyd-Franklin, 1989, p. 166). Instead of assigning various levels of responsibility for the problem, various levels of empowerment

should be determined and encouraged. At what level is the family empowered to create a life of relative normalcy?

In addition, families cannot be categorized into any particular model. As previously mentioned, each family responds differently to the impact of a chronic illness, according to their inherent strengths, weaknesses and needs. Families vacillate from requiring a great deal of assistance and guidance, to requiring a minimal amount of support according to the situation, for example, diagnosis versus remission of the ill family member. It is not a linear progression, rather it must be cyclical (see Figure 2). Each family will react to each situation differently, therefore the model used to determine interventions must be flexible to allow for these different levels of capabilities within the family unit, intertwined with basic assumptions regarding families with chronic illness (Leahey & Wright, 1985) (see Figure 3). The crisis section (see Figure 2) of the model applies to the family that is in crisis. These families require a great deal of assistance and may be incapable of arriving at solutions. The health professional provides solutions according to the family's capabilities. In the adjustment section of the model the level of empowerment remains low, but the family is more capable of defining the problem and is responsible for arriving at the solution. The adjustment portion of the model is applicable to a family that is slowly adjusting to the illness, but tunnel vision prevents them from regaining control and returning to a normal way of life. While the focus of the family still remains on the ill family member and not on the other family members , they are technically capable of providing care and obtaining services due to their high levels of responsibility to the solution. However, at this phase the family's empowerment level

remains low. In the normalcy aspect of the model, the family has the power to take action (the feeling of empowerment is high) as is their ability to determine a solution. Very little help is required from the health professional for the family is effectively returning to a normal family life where the focus is on every family member, rather than just the chronically ill member. The needs of every family member are being met.

To apply this model to military families with chronically ill children, the unique stressors experienced by military families must be integrated into the model. For this study, stressors such as moving to a new duty station (geographic mobility), spouse absence, and working within the military medical system have been inserted into the appropriate phases of the models (see Figure 4). The helping behaviors remain the same. Moving to a new duty station may be a crisis to one family because of a break in continuity of care for their child and social isolation, whereas another family may move into the adjustment phase. A family with an absent spouse may require the helping behaviors of the adjustment phase, but this family may too swing to the crisis phase of the model if the child becomes acutely ill or relapses during the spouse's absence. The return of the spouse may bring the family to the adjustment phase if role conflicts occur. Regardless of the situation, the phase the family falls into is dependent on their ability to take responsibility for the solution and how empowered they feel to arrive at the appropriate solution.



Appropriate Interventions for Phases
Crisis - aimed at Cognitive Level
Adjustment - aimed at Affective Level
Normalcy - aimed at Behavioral Level

Phases of the Illness
1. **Diagnosis**
2. **Adjusting to the illness**
3. **Returning to normal family life**
4. **Complications developing**
5. **Returning to normal family life but concerned with potential complications**
6. **Death of the child**
7. **Grieving**

Phases associated with same numbered categories within model.

FIGURE 2: A Model for Assisting Families with Chronically Ill Family Members

1. There are predictable points of family stress when there is chronic illness of a child
    a. Missed developmental milestones
    b. Poor growth, mentally, physically and developmentally

2. Families vary in their tolerance for the patient's physical condition.

3. Families under stress tend to hold to previously used patterns of behavior, whether they are effective or not.

4. Families usually go through grief-loss process following the diagnosis of a disabling condition.
    a. Patient grieves the loss of his/her health
    b. Family members grieve the loss of their formerly healthy family member.

5. Families play a significant role in the encouragement or discouragement of the family member with a chronic illness to participate in particular therapies.

6. Families initially react to particular "illness behaviors".
    a. Family focuses on the ill member, creating dependency.
    b. Unable to recognize the real needs of the ill family member.

7. Many families have difficulty adjusting to chronic illness because they either have incorrect or inadequate disease related information.

8. When there is a chronic illness, families must adjust to changes in expectations for each other.

9. A family's perception of the illness event has the most influence on their ability to cope.
    a. Will influence family's ability to adjust and adapt
    b. A family does not have to accept an illness

Adapted from Leahey & Wright (1985, pp. 61-65)

FIGURE 3: Basic Assumptions about Families with Chronically Ill Children

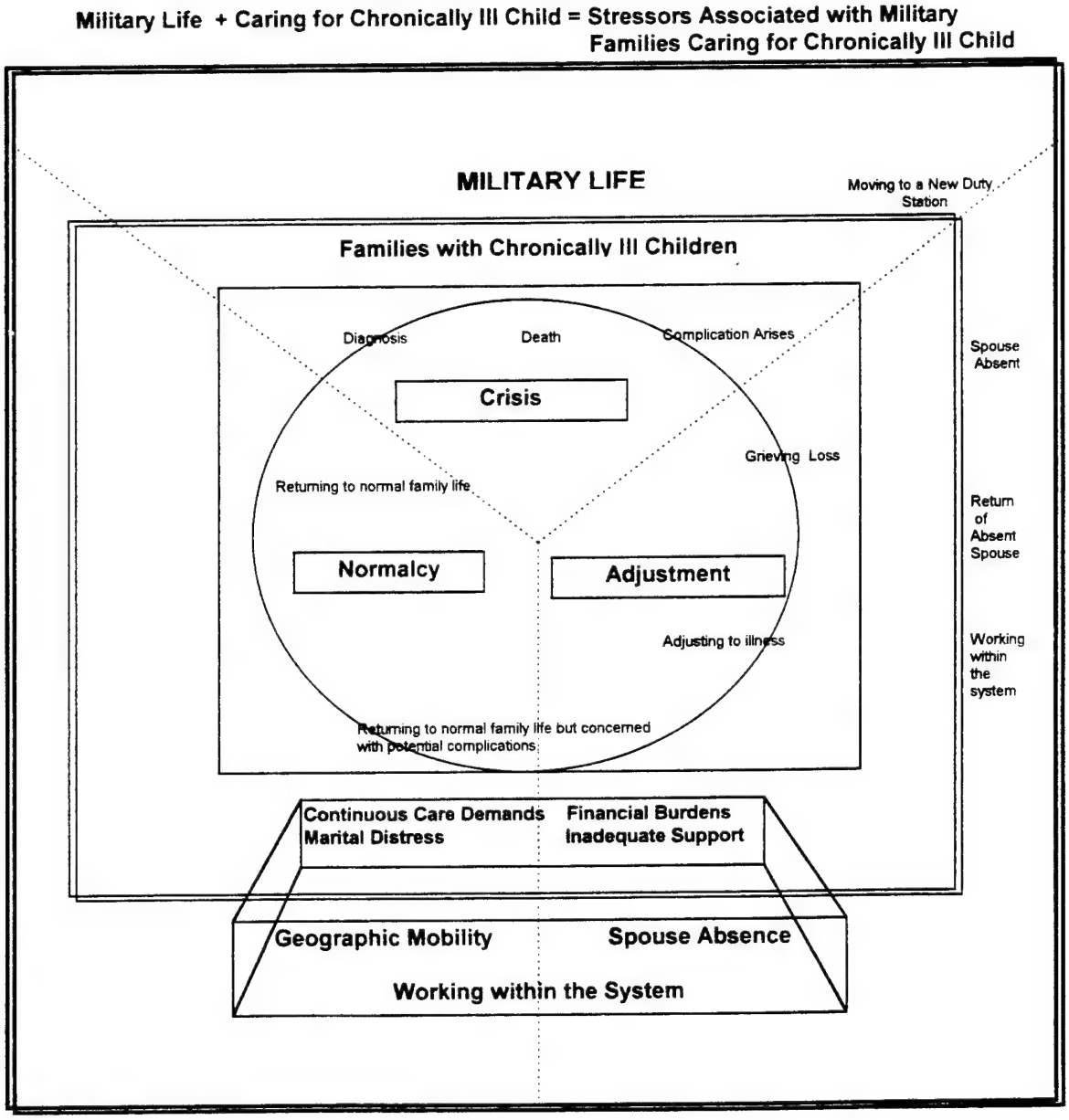


FIGURE 4: A Model for Assisting Military Families with Chronically Ill Children

Methodology

Design

To identify problems and needs these families have in obtaining and providing care for their children within the military and the military medical system the **Military Families with Chronically Ill Children - A Needs Assessment Questionnaire** was designed and face/content validity were evaluated. The needs assessment questionnaire is based on information obtained in the literature, questions being congruent with the concepts of the framework outlined in the previous sections. The purpose of the needs assessment questionnaire is to determine not only the needs and problems, but the service delivery requirements for military families with chronically ill children. More specifically, the questions to be answered through the implementation of the instrument are the following: 1) what unique stressors do military families with chronically ill children experience? 2) what are the family's perceived needs in regards to medical support and services provided by the military medical system? 3) is the family receiving adequate and appropriate support from the military community? and 4) would the case management services fill these needs?

Content Validity

To ensure the questionnaire includes items which represent the domains identified from the review of the literature, content validity must be determined prior to implementation. Ten experts within the Seattle-Tacoma area were identified to take part in the determination of content validity. Experts identified for inclusion in the determination of content validity included individuals working closely with military families with

chronically ill children, such as EFMP (Exceptional Family Member Program) coordinators, military Pediatric Nurse Practitioners, and one military case manager. These individuals are familiar with and well-versed in helping military families with chronically ill children. They were asked to: 1) determine the relevancy of each item included in the questionnaire, 2) determine the phase of the conceptual framework the item addresses, and 3) link items with specific research objectives identified within the purpose statement. These tasks were accomplished through the experts completing two evaluation questionnaires; Expert Evaluation Questionnaire #1 and Expert Evaluation Questionnaire #2 (Appendices B & C). Evaluation Questionnaire #1 asked the experts to review the questionnaire and to match the item with the research objective they believe the item is targeted to accomplish. The experts were asked to assign each item to the phase of the conceptual framework they feel is applicable based on the content within the item. They were also requested to provide any comments or suggestions helpful for revision. Evaluation Questionnaire #2 required the expert to ascertain the relevance of each item included within the questionnaire based on their expertise and experience in working with military families caring for chronically ill children.

Each expert received a copy of the: 1) Master's Thesis Proposal, 2) Military Families with Chronically Ill Children - A Needs Assessment Questionnaire, 3) Evaluation Questionnaire #1, 4) Evaluation Questionnaire #2, and 5) an introductory letter including instructions and desired timelines for completing the questionnaires. After completion, the experts returned the evaluation questionnaires in the postage paid envelope within two weeks of receipt.

Face Validity

For the purpose of the this project, a verification of face validity was conducted to determine: 1) the clarity of instructions and questions within the questionnaire, 2) the accuracy of each item and associated response set, 3) if the domains of content addressed are comprehensive, and 4) if the items chosen for inclusion are relevant. These objectives was accomplished through the families providing answers to questions included in the Families Evaluation Questionnaire (Appendix D). Each respondent was asked to complete the needs assessment questionnaire simply to judge if the present format was easy to follow and aided in completion within a minimum amount of time. For this project, no data was taken from the completed needs assessment questionnaires.

Protection of Human Subjects

Consent for this project was obtained through the University of Washington's Human Subjects Institutional Review Board, the thesis committee and the Commander of the hospital from which the sample population was drawn. The Human Subjects Review Board guarantees and ensures the protection of the welfare and rights of human subjects to be studied in research projects. In addition, a survey control number was obtained from the Air Force Institute of Technology (AFIT). A Survey Control Number (SCN) is issued to all questionnaires to be administered to active duty military members and their dependents and again guarantees the rights and welfare of survey participants.

Sample and Setting

The sample consisted of 95 parents of chronically ill children. Criteria for inclusion were that at least one parent is an active duty military member of the United States Armed Forces and the family must be enrolled in the Exceptional Family Member Program. The sample population was a convenience sampling of those families with at least one active duty parent who is an enlisted member. McChord AFB in Tacoma, Washington was selected as the site from which the sample once Command approval was obtained. Of the 95 families sampled, 22 of the families chose to participate in the verification of face validity. Packets containing questionnaires were mailed to 95 families, five were returned undelivered, 2 were returned completed from families with an active duty officer. A total of twenty questionnaires were completed and returned from families enrolled in the EFMP and with at least one active duty member. The response rate was 22.7%.

Because the determination of face validity was being conducted on federal government employees and their dependents, the survey was implemented in the following manner. Pending approval of the military command, the questionnaire was delivered to the Exceptional Family Member Program office located on McChord AFB and distributed to selected enrollees. Each participant received a: 1) Military Families with Chronically Ill Children - A Needs Assessment Questionnaire, 2) Families Evaluation Questionnaire with an attached cover letter. The letter described implied consent through the completion of the questionnaire, procedures of ensuring anonymity, and instructions on completing the questionnaire. In addition, the letter provided a description of the purpose of the project and instructions for reviewing the questionnaire and completing the Evaluation

Questionnaire. There were no tangible incentives offered for completing the survey and the evaluation questionnaire, nor was any coercion, from either the Command or myself, used in having the questionnaires completed. Because of the guaranteed anonymity, neither my military rank or the rank/rate of the parents was an issue. The participants were asked to complete and return the questionnaires within 10 days of receipt. The questionnaires were returned via the mail in the postage-paid envelopes attached to the questionnaires. A phone number was provided to which the parent completing the questionnaire might call if questions arose.

Data Analysis Procedures

Data analysis of all questionnaires were performed through the use of grouped frequency distributions in order to tally all responses. Responses provided by the experts and families to open-ended questions have been transcribed, summarized and reviewed (Appendix E, Appendix G). Responses to Expert Evaluation Questionnaire #2 were used in the calculation of instrument CVI (Content Validity Index) and item CVI. Results obtained are discussed in the following sections.

Results

Content Validity

The experts were asked to complete and return the questionnaire within two weeks of receipt. Of the ten packets mailed, five were returned. Analysis of the data was accomplished through the use of frequency distributions to tally all responses obtained from the five returned Evaluation Questionnaires #1 and #2. All comments and suggestions provided by the respondents in answering the open-ended questions of Evaluation Questionnaire #1 were transcribed and summarized (Appendix E). The main objectives of Evaluation Questionnaire #1 were to have the experts: 1) determine the phase of the conceptual framework each item in Needs Assessment Questionnaire addresses and 2) link each item within the Needs Assessment Questionnaire with the specific research objectives identified within the purpose statement.

The conceptual framework was formulated based on information concerning families with chronically ill children and combined with concepts regarding military families derived from a review of the literature. This framework powered the development of the questionnaire and includes three phases: 1) Crisis, 2) Adjustment and 3) Normalcy. Prior to the distribution of the Expert Evaluation Questionnaire #1 a Key for Evaluation Questionnaire #1 (Appendix F) was developed designating the phases of the conceptual framework to each of the applicable items included within the Needs Assessment Questionnaire. By using the tallied responses provided by the responding experts, a comparison of the phases identified by myself and those identified by the experts was made (Table 1).

TABLE 1
Comparison of Framework Phases Identified for Questionnaire Items

Question #	Phases of Framework Identified by Author	Phases of Framework Identified by Experts
4	Crisis	Crisis
5 & 6	Crisis	Crisis Adjustment
7 & 8	Crisis	Crisis Adjustment
9	Adjustment	Adjustment
10	Crisis Adjustment	Adjustment
11	Crisis	Adjustment Normalcy
15	Crisis Adjustment	Adjustment Normalcy

One expert wrote in the additional comments that the phases of Crisis and Adjustment could not be delineated separately. This respondent also felt that the phase of the framework applicable to the family was dependent on the family's perception of the situation. The only item in which there was a major difference of opinion between myself and the experts was with Question #11. Question #11 asked the parents to identify

services that might be helpful to their family during a PCS (Permanent Change of Station). The experts responded with Adjustment and Normalcy when asked to which phases of the conceptual framework did this question pertain.

The research objectives identified to provide the basic structure of the Needs Assessment questionnaire were the following: 1) what unique stressors do military families with chronically ill children experience? 2) what are the family's perceived needs in regards to medical support and services provided by the military medical system? 3) is the family receiving adequate and appropriate support from the military community? and 4) would case management services fill these needs? Prior to distributing Expert Evaluation Questionnaire #1, the same key used for the identification of the framework phases, Key for Evaluation Questionnaire #1, also included the research objectives to be answered by each item in the questionnaire. Again, using the tallied responses of the returned expert questionnaires, a comparison of the proposed research objectives identified by myself and those identified by the experts was compiled (Table 2).

TABLE 2
Comparison of Identified Research Objectives for Questionnaire Items

Question #	Research Objective Identified by Author	Research Objective Identified by Experts
4	Perceived Needs	Perceived Needs Appropriate Support Case Management
5 & 6	Perceived Needs	Perceived Needs Appropriate Support
7 & 8	Perceived Needs	Perceived Needs Appropriate Support
9	Unique Stressors	Unique Stressors Appropriate Support
10	Perceived Needs Unique Stressors	Perceived Needs Appropriate Support
11	Perceived Needs Unique Stressors	Perceived Needs Appropriate Support Case Management
12	Perceived Needs Case Management Appropriate Support	Perceived Needs Case Management
13	Perceived Needs Case Management	Perceived Needs Case Management
14	Perceived Needs Case Management	Perceived Needs Case Management Appropriate Support
15	Perceived Needs Case Management	Perceived Needs Appropriate Support Unique Stressors

The experts' responses agreed the research objectives would be answered through the implementation of the questionnaire. The responses of the experts indicate additional research objectives, other than those identified by myself, were addressed. Unfortunately, only two items were singled out in identifying the unique stressors of military families with chronically ill children. One respondent wrote the research objectives were biased and did not inquire about the support and the services families might currently be receiving or had received. This expert felt there was no place for the family to write in the adequate and appropriate support they were presently receiving and the questionnaire was biased and led the families to believe they were not receiving any support at all from the military.

The last portion of the Experts' Evaluation Questionnaire #1 required the experts to evaluate the general format of the questionnaire and the domains addressed by the items. Table 3 summarizes the tallied responses of the experts.

TABLE 3
Tallied Responses of Experts Regarding Format/Domains

Question	Response		
	Yes	No	Maybe*
Do the items of the questionnaire effectively address those concerns of military families with chronically ill children?	4	1	
Are there items of concerns to military families with chronically ill children which have been omitted?	1	2	2
Are the response sets of each item complete?	4	1	
Are the items appropriately worded for the population targeted?	4	1	
Is the information within each item and response set accurate?	5		
Are the questions and instructions easy to read and understandable?	5		
Is the length of the questionnaire appropriate?	5		

*'Maybe' option added by experts.

Again, one expert respondent felt the Needs Assessment Questionnaire had "an underlying message that these parents did not get support. We do not know that." The expert goes on to say there are no questions that let the families identify services already available to them and the items of the questionnaire imply services are completely lacking. All other expert comments were positive and criticisms were constructive. These

comments and suggestions provided for improvement and revision of the questionnaire have been summarized and included in Table 4.

TABLE 4
Comments and Suggestions For Revisions/Improvement Format/Domains

How does the child's chronic illness affect the active duty member's promotion eligibility/base/duty promotion? How does that affect the active duty member's feelings toward his/her child?
Currently available resources?
What is the age and the diagnosis of the child with the chronic illness?
When was the diagnosis made?
How far away is your family support system?
At what type of base is your family stationed?
Does your family receive their medical care at a military clinic, military hospital or military medical center?
How long has your family been stationed at this base?
Is the person completing the survey the active duty member?
Include step-mother and step-father somewhere in demographics as many military families have "combination families."
Under definition questions (#1, 2, #3) - add option of special education/learning environment.

The assessment of content validity was done by utilizing the data received from Evaluation Questionnaire #2 and determining the Content Validity Index (CVI) as described by Waltz, Strickland & Lenz (1984). The experts were asked to determine the relevancy of each item within the questionnaire using a 4-option rating scale (1 = not relevant ; 2 = unable to assess relevance without item revision; 3 = relevant but needs minor alteration; 4 = very relevant and succinct) (Lynn, 1986). The CVI of each item was calculated by determining the proportion of experts who rated the item as content valid (a rating of 3 or 4). After computing the CVI for each item, the CVI for the entire instrument was calculated by using the proportion of items within the questionnaire determined to having content validity. Table 5 identifies the CVI for each item and the actual CVI for the instrument in its entirety. Twenty-two items received either a rating of 3 or 4. One item (Question #12) received an expert rating of 2 (unable to assess relevance without item revision) thereby the item CVI was .80. According to Lynn (1986), any item receiving a score of less than 0.83 must be revised or discarded. The CVI for the total instrument was 0.99 out of a possible CVI of 1.00. Per the expert's ratings the instrument and the items within the questionnaire have been determined to contain content validity with the exception of Question #12 which will be revised at a later date.

TABLE 5
Experts Ratings for Each Item/Item CVI/Instrument CVI

Question #	Given Option Rating by Experts of 1	2	3	4	Item CVI
1				5	1.00
2				5	1.00
3			1	4	1.00
4			1	4	1.00
5				5	1.00
6			1	4	1.00
7				5	1.00
8			1	4	1.00
9			2	3	1.00
10			1	4	1.00
11			1	4	1.00
12		1		4	.80
13			1	4	1.00
14				5	1.00
15			2	3	1.00
16				5	1.00
17				5	1.00
18				5	1.00
19				5	1.00
20				5	1.00
21				5	1.00
22				5	1.00
23				4*	1.00

Total CVI = (22 items receiving CVI of 1.00) + (1 item receiving CVI of .80)

Total Number of Items

$$\text{Total CVI} = \frac{22.0 + .80}{23} = 0.99$$

* 1 Missing response

Face Validity

To accomplish the determination of face validity each family was asked to complete the Needs Assessment Questionnaire and include answers to the open-ended questions. These responses were transcribed (Appendix G) and will be reviewed in the following section. Data provided by the families in completing the Needs Assessment Questionnaire will not be used at this time. The families were also asked to complete the Families Evaluation Questionnaire. The data obtained from the Families Evaluation Questionnaire was analyzed by utilizing grouped frequency distributions to tally the responses (Table 6).

TABLE 6
Families Evaluation Questionnaire
Tallied Responses

Question	Response	
	Yes	No
Are the instructions easy to read and understandable?	20	0
Are the questions easy to read and understandable?	18	1 (*)
Are there any areas of concern to you and your family which have not been included in the questions?	4	16
Are there any questions which you believe are not important or do not apply to your family?	3	17
Is the information included within each question accurate?	18	1 (*)
Are there any questions which include language or terms which are offensive?	1	18 (*)
Are there any questions that contain jargon or terms which are unclear?	0	20
Is the questionnaire too lengthy or too short? In other words, would the length of the questionnaire interfere in your completing the questionnaire?	1	18 (*)

(*) 1 Missing response

Over 90% of the participating families agreed: 1) the format of the questionnaire was acceptable, 2) the information within the questions and the response sets were accurate,

and 3) the instructions and questions were easy to read and understandable. 85% of the families responded positively in regards to the items of concern addressed within the questionnaire were complete. 15% of the families were of the opinion items of concern to their family were omitted or questions within the questionnaire were not applicable to their family and their chronically ill child. Comments and suggestions provided by the families which pertain to the items of concerns not-applicable to the families or concerns of the families omitted have been summarized in Table 7.

TABLE 7
Summary of Concerns Omitted/Not-Applicable

Omitted Concerns
More support during frequent deployments.
Concerns of the active duty member regarding discharge due to missed work, sub-standard performance due to stress of having chronically ill child.
Concerns of the active duty member regarding derogatory comment from and to peer about individuals work performance and lost time at work.
Concerns regarding lack of support when more than one child in the family is chronically ill or has special needs.
Concerns regarding family experiences when child is in remission.
Not-applicable concerns
Child is chronically ill, but did not require hospitalization.
Child has disabilities, but is not chronically ill.
The term 'chronic illness' is offensive.

The final portion of the family evaluation revolves around the compilation of comments provided by families in response to the open-ended questions asking for additional comments and alternative responses other than those provided within the response set within each item of the Needs Assessment Questionnaire. The underlying themes have been summarized and included in Table 8.

TABLE 8
Apparent Themes of Responses to Needs Assessment Questionnaires

Definition of Chronic Illness incomplete.
The need for more information regarding how child's illness will affect child, resources available.
Marital distress.
Difficulties experienced during TDYs (Temporary Duty).
Child care problems.
Using Emergency Room after hours.
Exchange of information to new duty station during PCS.
Lack of continuity of care.
More information and education in caring for child.
Constant changeover in military medical staff.
Financial concerns.
Support of active duty member from military community/supervisors/commanders.
Knowledge of the parents not respected by medical community.

Many of the comments provided by the parents were positive. These families were very happy with the care and the support they and their chronically ill child received. Complimentary statements were made regarding the services available from Madigan Army Medical Center and the support received by McChord AFB, both located in Tacoma, WA.

Discussion

Military families caring for chronically ill children have the combined stressors of caring for their child combined with the rigors of military life. To explore the difficulties military families face in caring for their child the Military Families with Chronically Ill Children - A Needs Assessment Questionnaire was developed. In designing the questionnaire a conceptual framework, Stressors Associated with Military Families Caring for Chronically Ill Children, was formulated to provide the basic structure of the questionnaire. The framework combines the established stressors of families caring for their chronically ill child with the stressors of military life. Because of the paucity of literature regarding military families with chronically ill children, many of the unique stressors identified for inclusion in the items of the questionnaire were based on personal experiences and observations made while working with these families.

In addition to creating a conceptual framework, research objectives were created to give substance to and identified domains for the inclusion within the items of the questionnaire. The main objectives to be accomplished in implementing the instrument, as previously stated, are: 1) what unique stressors do military families with chronically ill children face? 2) what are the family's perceived needs in regards to medical support and services provided by the military medical system 3) is the family receiving adequate and appropriate support from the military community? and 4) would case management services fill these needs?

objective, the experts asked to perform a verification of content validity were also asked to link the items of the questionnaire to the established research objectives. From the results obtained, the research objectives would be accomplished in implementing the questionnaire. From the results of the responses however, the one research objective not fully addressed was the objective identifying the unique stressors military families with chronically ill children face.

The experts were also asked to identify the applicable phases of the conceptual framework to which they believed certain items within the questionnaire pertained. The results indicate the experts were of the opinion the phases of Crisis and Adjustment were well represented within the items. The phase of Normalcy however, was not thoroughly explored within the items of the questionnaire. In designing the questionnaire initially, items concerning the Normalcy phase of the conceptual framework had been included within the questionnaire. To obtain approval for the implementation of the questionnaire and the necessary assignment of a Survey Control Number from the Air Force, it was recommended that those questions be discarded. Perhaps in future revisions, the questions can again be included within the questionnaire.

The primary purpose of this thesis was to create a questionnaire to assess the needs of military families with chronically ill children and perform a verification of content validity of the questionnaire. According to the experts asked to perform the content validity verification, the Needs Assessment Questionnaire contains content validity. One item (Question #12) was deemed to not have content validity and will be revised before administering the Needs Assessment Questionnaire.

To ensure the questionnaire appealed to the targeted population a verification of face validity was performed. The response rate was respectable for a questionnaire survey, especially considering the families were asked to complete two questionnaires. The families responded positively to the format of the questionnaire. Most items within the questionnaire and the response sets were accurate and complete. However, some items of concerns were omitted. These areas of concerns included: 1) how the child's illness affects the active duty military member's career potential, 2) child care problems, 3) constant changeover in medical staff, 4) financial concerns, 5) the positive aspects of being a military family caring for a chronically ill child, 6) the family with the child in remission and 7) the definition of chronic illness is incomplete. These concerns will be added to the questionnaire during future revisions. Items not applicable to families included: 1) the definition of chronic illness does not cover or apply to those children with physical disabilities and developmental delays and 2) the term chronic illness. In future revisions those areas of concerns that were omitted will be included in the questionnaire and the title of the Needs Assessment Questionnaire will be changed to Military Families Caring for Children with Special Needs. In addition, the definition of chronic illness will be expanded to include those children who have emotional, physical and medical problems resulting in special needs.

It is apparent military families caring for chronically ill children do experience marital distress, continuous care demands and possibly financial burdens. It is also clear from the families' comments in response to the questionnaires, that for most families many services are available but still there are some needs which are not being met. It is

imperative that these needs be explored through the implementation of a revised and refined Needs Assessment Questionnaire in order to understand the specific needs of the families and if these needs can be filled with case management programs or with family-centered care programs.

Future Plans

The conceptual framework requires refinement. The basic structure of the framework is viable, being circular rather than linear. However, the phases are incomplete and in the future revisions a new phase needs to be inserted between the Adjustment and Normalcy phase of the framework which focuses primarily on the affective functioning of the family. Also, it is unclear as to whether there are distinct and easily delineated phases within the framework or more an overlapping of phases. In future questionnaires, open-ended questions pertaining to the experiences and emotions of families will have to be included to determine how the phases overlap and if there is a need for an additional phase within the conceptual framework. Additionally, questions pertaining to the Normalcy phase will be included for evaluation.

The questionnaire has been found to have both face validity and content validity. Future plans for implementation of the questionnaire include the following: 1) a comparison of services available and services needed at bases where clinics are the only source of medical care versus bases where small hospitals provide services versus bases which have services provided by large military medical centers, 2) a comparison of responses provided by the spouse of the active duty member versus responses provided by the active duty member, and 3) a comparison of the needs of the families where the active

responses provided by the spouse of the active duty member versus responses provided by the active duty member, and 3) a comparison of the needs of the families where the active duty member is enlisted versus the needs of the families where the active duty member is an officer.

The results of future implementation of the questionnaire will be utilized in formulating a report to be presented along with a proposal for the development of appropriate programs to the powers that be within the Air Force. I foresee a program that combines the principles of case management with the resources of military families caring for their chronically ill children. It is strikingly clear the predominant energy needed to be tapped to fuel any such program instituted will be the resource that it is already present in each and everyone of these families. That resource being the incredible strength, determination and unswerving desire of these families to provide and obtain the best care possible for their children.

References

Boyd-Franklin, N. (1989). Black families in therapy. New York: The Guilford Press.

Brickman, P. (1982). Models of helping and coping. American Psychologist. 37, 368-381.

Davis, H. (1993). Counseling parents of children with chronic illness or disability. Leicester, UK:BPS Books.

Desguin, B.W., Holt, I.J., & McCarthy, S.M. (1994). Comprehensive care of the child with a chronic condition. Part 1. Understanding chronic conditions in childhood. Current Problems in Pediatrics. 24, 199-218.

Jessop, D.J. & Stein, R.E.K. (1988). Essential concepts in the care of children with chronic illness. Paeditrician. 15, 5-12.

Leahey, M. & Wright, L.M. (1985). Intervening with families with chronic illness. Family Systems Medicine. 3 (1), 60-69.

Leonard, B.J., Brust, J.D., & Nelson, R.P. (1993). Parental distress: Caring for medically fragile children at home. Journal of Pediatric Nursing. 8 (1), 22-30.

Lewis, C.C., Alford-Winston, A., Billy-Kornas, M, McCaustland, M.D., & Tachman, C.P. (1992). Care management for children who are medically fragile/technology-dependent. Issues in Comprehensive Pediatric Nursing. 15 , 73-91.

Lynn, M. R. (1986). Determination and quantification of content validity. Nursing Research. 35 (6), 382-385.

Marsh, R.H. (1976). Mobility in the military. In H. McCubbin, B. Dahl & E. Hunter (eds.), Families in the Military System. (pp. 92-111). Beverly Hills:Sage Publications.

Martinez, N.H, Schreiber, M.L., & Hartman, E.W. (1991). Pediatric nurse practitioners: Primary care providers for chronically ill children at home. Journal of Pediatric Health Care. 5 (6), 291-298.

McCubbin, H.I., & Dahl, B.B. (1976). Prolonged family separation in the military: A longitudinal study. In H. McCubbin, B. Dahl & E. Hunter (eds.), Families in the Military System. (pp. 112-144). Beverly Hills: Sage Publications.

Nunnally, J.C. (1967). Psychometric Theory. San Francisco: McGraw-Hill Book Company.

Pace, J.C. (1985). An advocacy model for health care professionals. Family and Community Health. Feb., 77-87.

Perrin, J. (1985). Introduction. In N. Hobbs & J. Perrin (eds.), Issues in the Care of Children with Chronic Illness. (pp. 1-10). San Francisco: Jossey-Bass.

Saylor, J. (1992). TQM Field Manual. San Francisco, CA: McGraw-Hill.

Steele, S. (1993). Nurse and parent collaborative case management in a rural setting. Pediatric Nursing. 19 (6), 612-615.

Stein, R.E.K., Bauman, L.J., Westbrook, L.E., Coupey, S.M. & Henry, T.I. (1993). Framework for identifying children who have chronic conditions: The case for a new definition. The Journal of Pediatrics. 122 (3), 342-347.

Walker, J.G., Manion, I.G. & Cloutier, P.F. (1992). Measuring marital distress in couples with chronically ill children. The dyadic adjustment scale. Journal of Pediatric Psychology. 17 (3), 345-357.

Waltz, C.F., Strickland, O. L. & Lenz, E. R. (1984). Measurement in Nursing Research. Philadelphia: F.A. Davis Company.

Appendix A

Military Families with Chronically Ill Children

A Needs Assessment Questionnaire

MILITARY FAMILIES

with

Chronically Ill Children

Needs Assessment Questionnaire

University of Washington
School of Nursing
Department of Parent and Child Nursing
Needs Assessment Questionnaire

Thank-you very much for taking the time to complete this questionnaire. The information gathered from this study will help to support the need for and development of case management approach programs which will reduce the burdens and frustrations military families such as your own experience daily in providing and obtaining care for your chronically ill child.

Purpose of the Study: I am conducting a study to uncover the thoughts and concerns military families with chronically ill children experience in obtaining and providing care for their children. Specifically, the study will ask questions on the following: time of diagnosis, care demands, marital distress, financial burdens, support or lack thereof, relocation issues, spouse absence and working within the system. In addition, I am very interested in any suggestions you have regarding programs and services you feel might be helpful.

Procedures and Confidentiality: If you are willing to participate, please take time to complete this questionnaire. When you are finished, place the questionnaire in the postage paid envelope attached and drop it in the mail. Completion and return of the questionnaire will serve as implied consent to participate.

Risks: There is minimal risk associated with this study. Risks may include discomfort as some of the questions may seem personal and cause you to recall painful events. Participation or non-participation in this study will not affect your medical care, benefits, or other entitlements. There are no costs or reimbursement for the study.

Voluntary Participation and Confidentiality: All questionnaires are anonymous and will be identified by code numbers which in no way can be linked to you. Please do not write your name or any information that might identify you. If you have any questions, please contact me at (206) 335-4156.

Again, thank-you for your cooperation!

Susan Morgan, RN
Graduate Student
University of Washington

1. **Due to your child's illness, which of the following items are required on a daily basis?**

   a. **Medications**

   b. **Special diet**

   c. **Equipment**

   d. **Treatments**

   e. **All of the above.**

   f. **None of the above.**

2. **Please indicate which applies to your child and his/her illness:**

   a. **The illness affects his/her daily activities for a total of three months out of the year.**

   b. **At the time of diagnosis your child was hospitalized for up to a month.**

   c. **During the last year your child has spent at least a total of a month in the hospital because of his/her illness.**

   d. **All of the above.**

   e. **None of the above.**

3. **Approximately how many days of school has your child missed in the last year because of his/her illness:**

   a. **10 days or less**

   b. **11 - 20 days**

   c. **21 - 30 days**

   d. **31 - 40 days**

   e. **Does not attend school.**

   Reason_____

4. **Think back to the time your child was diagnosed with his/her chronic illness/disorder. Which of the following items do you feel might have helped your family during this time?**

   a. **Being able to talk with other families having children diagnosed with the same illness as your child.**

   b. **More information on how the illness would affect your child emotionally and physically.**

   c. **More information on resources and community services available to your family.**

   d. **Help with obtaining resources and services for your child/family.**

   e. **All of the above.**

   f. **None of the above.**

   g. **Other (please specify):**

   _____

   _____

5. **At the time of diagnosis did you and your spouse experience any problems with your marriage such as difficulty in communicating, feelings of anger towards one another and decreased intimacy?**

   a. **Yes**

   b. **No**

   c. **Does not apply.**

6. **If you answered Yes to Question 5 which of the following services do you feel might have helped in decreasing the above problems you were experiencing in your marriage?**

   a. **Speaking with a Chaplain, Rabbi or Priest.**

   b. **Speaking with a qualified marriage counselor as a couple.**

   c. **Speaking with a married couple who have a child with a chronic illness/disorder.**

   d. **Respite care - A qualified professional coming into your home and providing care to your child in order to allow you to take care of yourself and spend time with spouse.**

   e. **Other (please specify):**

   _____

   _____

7. **If you have other children, have you noticed any changes in their behavior such as pulling away from the family, acting needy or hitting and fighting more?**

   a. **Yes, I have seen changes in my other children.**

   b. **No, I have not seen changes in my other children.**

   c. **Does not apply - I have no other children.**

8. If you answered Yes to Question 7 which of the following services do you feel might help your other children cope with the changes in your family's lifestyle due to your child's illness/disorder?

   a. Sibling support groups.

   b. Speaking with a qualified child psychiatrist or counselor.

   c. Providing parents with qualified health professionals to care for your ill child so you can spend "special" time with your other children at least on a weekly basis.

   d. Other (please specify):

   _____

   _____

9. During TDYs, deployments, training exercises, were any of the following experienced by the spouse left at home, in caring for your chronically ill child and handling daily obligations?

   a. Sadness

   b. Personal frustration associated with responsibilities.

   c. Feelings of anger towards spouse.

   d. Unexpected hospitalization of your chronically ill child.

   e. Child care problems.

   f. Changes in behaviors of children.

   g. Have not experienced a separation.

   h. None of the above.

   i. Other (please specify):

   _____

   _____

10. If you experienced any of the items listed in Question 9 , which of the following do you think might have helped the most?

a. Assistance in child care.

b. Assistance in running errands, taking care of chores.

c. Assistance with transportation to and from clinics.

d. Easy access to a professional to discuss your problems and concerns.

e. Other (please specify):

_____

_____

11. Prior to arriving at a new duty station (during a PCS), which of the following items listed below could make your move easier and less stressful?

a. A sponsor family who also have a chronically ill child (someone who understands the stresses of PCSing with a chronically ill child).

b. A list of phone numbers of physicians, clinics and medical facilities available in the area in case you need them.

c. We did not experience any difficulties during our PCS.

d. We have not had to PCS during our child's illness.

e. Other (please specify):

_____

_____

12. **Which of the following do you think contributes to the lack of continuity of care or a feeling like there is gaps in the care your child is receiving?**

    a. **Not having one physician who you can contact directly who is very familiar with your child's medical history and treatments.**

    b. **Having to use the Emergency Room after hours and explaining your child's medical history over and over.**

    c. **Not having one person helping you arrange services such as appointments and obtain resources such as equipment, special medications and treatments.**

    d. **I do not feel there is a lack in continuity of care.**

    e. **Other (please specify):**

    _____

    _____

13. **In providing continuity of care, which of the following do you feel would help?**

    a. **One health care provider (such as a physician or Pediatric Nurse Practitioner) that cared for and coordinated all services for your child.**

    b. **When PCSing having your provider from the old duty station communicate with a provider at the new duty station regarding your child's condition, treatments and history.**

    c. **Having a 24 hour telephone number that allows you to speak with a health professional concerning your child's condition or symptoms.**

    d. **Continuity of care is provided.**

    e. **Other (please specify):**

    _____

    _____

14. As a military family which of the following items worry you the most in caring for your chronically ill child?

a. Difficulties arranging care for your child.

b. Lack of continuity of care (feeling like nobody seems to know your child's medical problems as well as you do, you never see the same doctor).

c. Feeling you have no control over the care your child receives.

d. Working between the military medical system and the civilian medical system.

e. I have no difficulties or concerns in caring for my child.

f. Other (please specify):

_____

_____

15. **Which of the following services do you believe might have been helpful or would now be helpful. Also indicate in the space provided at which period in your child's illness did you feel you needed this help the most.**

Example:
Support at home with providing care for your child. 1,3

Periods in your child's illness

1	Diagnosis
2	During hospitalization
3	Discharge from hospital
4	During spouse absences
5	While PCSing
6	At all times

a. **Increased teaching and guidance in providing care to child.**

b. **Emotional support.**

c. **Help with marriage because of increased conflicts.**

d. **Assistance with paperwork in obtaining financial support, subsidies, equipment, treatments, etc.**

e. **Help in obtaining resources and services for your child.**

f. **Someone to talk with about your feelings, concerns your child's illnesses and the affect it is having on you and your family's life.**

g. **Received all the help our family/child needed.**

16. **How many children live with you?**

a. **One**

b. **Two**

c. **Three**

d. **Four**

e. **Five or more**

17. What are their ages?

_____

18. Are you:

a. Single

b. Married

c. Divorced

d. Widowed

19. What is your age?

a. Under 25

b. 26 - 30

c. 31 - 35

d. 36 - 40

e. 41 - 45

f. 46 - 50

20. If married, what is your spouse's age?

    a. Under 25

    b. 26 - 30

    c. 31 - 35

    d. 36 - 40

    e. 41 - 45

    f. 46 - 50

21. The active duty parent is:

    a. Wife/Mother

    b. Husband/Father

    c. Both husband and wife

22. The active duty parent is, or both parents are:

    a. Enlisted

    b. Officer

23. This page is provided for additional comments you might have in regards to services needed for your family and your chronically ill child.

Appendix B

Expert Evaluation Questionnaire #1

Content Validity - Framework/Research Objectives

Content Validity

Expert Evaluation Questionnaire #1

The research questions for which this survey was designed to answer are the following:

1) What unique stressors do military families with chronically ill children experience?

2) What are the family's perceived needs in regards to medical support and services provided by the military medical system?

3) Is the family receiving adequate and appropriate support from the military community?

4) Would case management services fill these needs?

Please review the attached proposal and answer the following questions.

Question #1, Question #2 and Question #3:

1. **Due to your child's illness, which of the following items are required on a daily basis?**

   a. **Medications**

   b. **Special diet**

   c. **Equipment**

   d. **Treatments**

   e. **All of the above.**

   f. **None of the above.**

Question #1, Question #2 and Question #3:

2. Please indicate which applies to your child and his/her illness:

a. The illness affects his/her daily activities for a total of three months out of the year.

b. At the time of diagnosis your child was hospitalized for up to a month.

c. During the last year your child has spent at least a total of a month in the hospital because of his/her illness.

d. All of the above.

e. None of the above.

3. Approximately how many days of school has your child missed in the last year because of his/her illness:

a. 10 days or less

b. 11 - 20 days

c. 21 - 30 days

d. 31 - 40 days

e. Does not attend school.

Reason_____

These questions are included to determine if the child's illness falls under the definition of chronic illness as discussed in the proposal. Are these questions necessary and appropriate?

A. Yes

B. No

Comments_____

_____

_____

_____

Question #4:

4. Think back to the time your child was diagnosed with his/her chronic illness/disorder. Which of the following items do you feel might have helped your family during this time?

a. Being able to talk with other families having children diagnosed with the same illness as your child.

b. More information on how the illness would affect your child emotionally and physically.

c. More information on resources and community services available to your family.

d. Help with obtaining resources and services for your child/family.

e. All of the above.

f. None of the above.

g. Other (please specify):

_____

_____

According to the conceptual framework described within the proposal (Table 4 - **A Model for Assisting Military Families with Chronically Ill Children**), to which of the following phases of the framework does this question pertain?

A. Crisis

B. Adjustment

C. Normalcy

D. None of the above.

Considering the research questions outlined above, which of the following does this question appear to answer?

A. **Unique stressors** of military families with chronically ill children.

B. **Perceived needs** in regards to medical supports and services.

C. Family receiving **appropriate support** from the military community.

D. **Case management** filling the needs of the family.

E. None of the above.

Question #5 and Question #6:

5. **At the time of diagnosis did you and your spouse experience any problems with your marriage such as difficulty in communicating, feelings of anger towards one another and decreased intimacy?**

   a. **Yes**

   b. **No**

   c. **Does not apply.**

6. **If you answered Yes to Question 5 which of the following services do you feel might have helped in decreasing the above problems you were experiencing in your marriage?**

   a. **Speaking with a Chaplain, Rabbi or Priest**

   b. **Speaking with a qualified marriage counselor as a couple.**

   c. **Speaking with a married couple who have a child with a chronic illness/disorder.**

   d. **Respite care - A qualified professional coming into your home and providing care to your child in order to allow you to take care of yourself and spend time with spouse.**

   e. **Other (please specify):**

   _____

   _____

According to the conceptual framework described within the proposal (Table 4 - **A Model for Assisting Military Families with Chronically Ill Children**), to which of the following phases of the framework does Question #6 pertain?

A. Crisis

B. Adjustment

C. Normalcy

D. None of the above.

Question #5 and Question #6:

Considering the research questions outlined above, which of the following does this question appear to answer?

A. **Unique stressors** of military families with chronically ill children.

B. **Perceived needs** in regards to medical supports and services.

C. Family receiving **appropriate support** from the military community.

D. **Case management** filling the needs of the family.

E. None of the above.

Question #7 & Question #8

7. **If you have other children, have you noticed any changes in their behavior such as pulling away from the family, acting needy or hitting and fighting more?**

   a. **Yes, I have seen changes in my other children.**

   b. **No, I have not seen changes in my other children.**

   c. **Does not apply - I have no other children.**

8. **If you answered Yes to Question 7 which of the following services do you feel might help your other children cope with the changes in your family's lifestyle due to your child's illness/disorder?**

   a. **Sibling support groups.**

   b. **Speaking with a qualified child psychiatrist. or counselor**

   c. **Providing parents with qualified health professionals to care for your ill child so you can spend "special" time with your other children at least on a weekly basis.**

   d. **Other (please specify):**

   _____

   _____

Question #7 & Question #8

According to the conceptual framework described within the proposal (Table 4 - **A Model for Assisting Military Families with Chronically Ill Children**), to which of the following phases of the framework does Question #8 pertain?

A. Crisis

B. Adjustment

C. Normalcy

D. None of the above.

Considering the research questions outlined above, which of the following does this question appear to answer?

A. **Unique stressors** of military families with chronically ill children.

B. **Perceived needs** in regards to medical supports and services.

C. Family receiving **appropriate support** from the military community.

D. **Case management** filling the needs of the family.

E. None of the above.

Question #9:

9. During TDYs, deployments, training exercises, were any of the following experienced by the spouse left at home, in caring for your chronically ill child and handling daily obligations?

a. Sadness

b. Personal frustration associated with responsibilities.

c. Feelings of anger towards spouse.

d. Unexpected hospitalization of your chronically ill child.

e. Child care problems.

f. Changes in behaviors of children.

g. Have not experienced a separation.

h. None of the above.

i. Other (please specify):

_____

Question #9:

According to the conceptual framework described within the proposal (Table 4 - **A Model for Assisting Military Families with Chronically Ill Children**), to which of the following phases of the framework does this question pertain?

A. Crisis

B. Adjustment

C. Normalcy

D. None of the above.

Considering the research questions outlined above, which of the following does this question appear to answer?

A. **Unique stressors** of military families with chronically ill children.

B. **Perceived needs** in regards to medical supports and services.

C. Family receiving **appropriate support** from the military community.

D. **Case management** filling the needs of the family.

E. None of the above.

Question #10:

10. If you experienced any of the items listed in Question 9 , which of the following do you think might have helped the most?

a. Assistance in child care.

b. Assistance in running errands, taking care of chores.

c. Assistance with transportation to and from clinics.

d. Easy access to a professional to discuss your problems and concerns.

e. Other (please specify) :

_____

_____

Question #10:

According to the conceptual framework described within the proposal (Table 4 - **A Model for Assisting Military Families with Chronically Ill Children**), to which of the following phases of the framework does this question pertain?

A. Crisis

B. Adjustment

C. Normalcy

D. None of the above.

Considering the research questions outlined above, which of the following does this question appear to answer?

A. **Unique stressors** of military families with chronically ill children.

B. **Perceived needs** in regards to medical supports and services.

C. Family receiving **appropriate support** from the military community.

D. **Case management** filling the needs of the family.

E. None of the above

Question #11:

11. Prior to arriving at a new duty station (during a PCS), which of the following items listed below could make your move easier and less stressful?

a. A sponsor family who also have a chronically ill child (someone who understands the stresses of PCSing with a chronically ill child).

b. A list of phone numbers of physicians, clinics and medical facilities available in the area in case you need them.

c. We did not experience any difficulties during our PCS.

d. We have not had to PCS during our child's illness.

e. Other (please specify):

_____

_____

Question #11:

According to the conceptual framework described within the proposal (Table 4 - **A Model for Assisting Military Families with Chronically Ill Children**), to which of the following phases of the framework does this question pertain?

A. Crisis

B. Adjustment

C. Normalcy

D. None of the above

Considering the research questions outlined above, which of the following does this question appear to answer?

A. **Unique stressors** of military families with chronically ill children.

B. **Perceived needs** in regards to medical supports and services.

C. Family receiving **appropriate support** from the military community.

D. **Case management** filling the needs of the family.

E. None of the above.

Question #12:

12. Which of the following do you think contributes to the lack of continuity of care or a feeling like there is gaps in the care your child is receiving?

a. Not having one physician who you can contact directly who is very familiar with your child's medical history and treatments.

b. Having to use the Emergency Room after hours and explaining your child's medical history over and over.

c. Not having one person helping you arrange services such as appointments and obtain resources such as equipment, special medications and treatments.

d. I do not feel there is a lack in continuity of care.

e. Other (please specify) :

_____

_____

Question #12:

Considering the research questions outlined above, which of the following does this question appear to answer?

A. **Unique stressors** of military families with chronically ill children.

B. **Perceived needs** in regards to medical supports and services.

C. Family receiving **appropriate support** from the military community.

D. **Case management** filling the needs of the family.

E. None of the above.

Question #13:

13. In providing continuity of care, which of the following do you feel would help?

a. One health care provider (such as a physician or Pediatric Nurse Practitioner) that cared for and coordinated all services for your child.

b. When PCSing having your provider from the old duty station communicate with a provider at the new duty station regarding your child's condition, treatments and history.

c. Having a 24 hour telephone number that allows you to speak with a health professional concerning your child's condition or symptoms.

d. Continuity of care is provided.

e. Other (please specify):

_____

_____

Considering the research questions outlined above, which of the following does this question appear to answer?

A. **Unique stressors** of military families with chronically ill children.

B. **Perceived needs** in regards to medical supports and services.

C. Family receiving **appropriate support** from the military community.

D. **Case management** filling the needs of the family.

E. None of the above.

Question #14:

14. As a military family which of the following items worry you the most in caring for your chronically ill child?

a. Difficulties arranging care for your child.

b. Lack of continuity of care (feeling like nobody seems to know your child's medical problems as well as you do, you never see the same doctor).

c. Feeling you have no control over the care your child receives.

d. Working between the military medical system and the civilian medical system.

e. I have no difficulties or concerns in caring for my child.

f. Other (please specify) :

_____

_____

Considering the research questions outlined above, which of the following does this question appear to answer?

A. **Unique stressors** of military families with chronically ill children.

B. **Perceived needs** in regards to medical supports and services.

C. Family receiving **appropriate support** from the military community.

D. **Case management** filling the needs of the family.

E. None of the above.

Question #15:

15. **Which of the following services do you believe might have been helpful or would now be helpful. Also indicate in the space provided at which period in your child's illness did you feel you needed this help the most.**

Example:
Support at home with providing care for your child. 1,3

Periods in your child's illness		
	1	**Diagnosis**
	2	**During hospitalization**
	3	**Discharge from hospital**
	4	**During spouse absences**
	5	**While PCSing**
	6	**At all times**

a. Increased teaching and guidance in providing care to child.

b. Emotional support.

c. Help with marriage because of increased conflicts.

d. Assistance with paperwork in obtaining financial support, subsidies, equipment, treatments, etc.

e. Help in obtaining resources and services for your child.

f. Someone to talk with about your feelings, concerns, your child's illnesses and the affect it is having on you and your family's life.

g. Received all the help our family/child needed.

According to the conceptual framework described within the proposal (Table 4 - **A Model for Assisting Military Families with Chronically Ill Children**), to which of the following phases of the framework does this question pertain?

A. Crisis

B. Adjustment

C. Normalcy

D. None of the above.

Question #15:

Considering the research questions outlined above, which of the following does this question appear to answer?

A. **Unique stressors** of military families with chronically ill children.

B. **Perceived needs** in regards to medical supports and services.

C. Family receiving **appropriate support** from the military community.

D. **Case management** filling the needs of the family.

E. None of the above.

Questions #16-22:

16. How many children live with you?

a. One

b. Two

c. Three

d. Four

e. Five or more

17. What are their ages?

_____

18. Are you:

a. Single

b. Married

c. Divorced

d. Widowed

Questions #16-22:

19. **What is your age?**

    a. **Under 25**

    b. **26 - 30**

    c. **31 - 35**

    d. **36 - 40**

    e. **41 - 45**

    f. **46 - 50**

20. **If married, what is your spouse's age?**

    a. **Under 25**

    b. **26 - 30**

    c. **31 - 35**

    d. **36 - 40**

    e. **41 - 45**

    f. **46 - 50**

21. **The active duty parent is**

    a. **Wife/Mother**

    b. **Husband/Father**

    c. **Both husband and wife**

22. **The active duty parent is, or both parents are:**

    a. **Enlisted**

    b. **Officer**

Questions #16-22:

These questions concern demographics. Are they complete?

A. Yes

B. No

If you answered No, please provide suggestions for revisions:

_____

_____

_____

_____

General

1. Do the items of the questionnaire effectively address those concerns of military families with chronically ill children?

   A. Yes

   B. No

   If you answered No please provide suggestions:

   _____

   _____

   _____

   _____

2. Are there items of concern to military families with chronically ill children which have been omitted?

   A. Yes

   B. No

   If you answered Yes please provide suggestions:

   _____

   _____

   _____

   _____

3. Are the response sets of each item complete?

   A. Yes

   B. No

   If you answered No, please provide the Question number and suggestions for revisions:

   _____

   _____

   _____

   _____

4. Are the items appropriately worded for the population targeted?

   A. Yes

   B. No

   If you answered No, please provide suggestions for revisions:

   _____

   _____

   _____

   _____

5. Is the information within each item and response set accurate?

   A. Yes

   B. No

   If you answered No, please provide suggestions for revisions:

   _____

   _____

   _____

   _____

6. Are the questions and instructions easy to read and understandable?

   A. Yes

   B. No

   If you answered No, please provide suggestions for revisions:

   _____

   _____

   _____

   _____

7. Is the length of the questionnaire appropriate? In other words, are there too many or too few questions in any category or overall?

   A. Yes

   B. No

   If you answered Yes, please provide suggestions for revisions:

   _____

   _____

   _____

Appendix C

Expert Evaluation Questionnaire #2

Content Validity - Item Relevance

Content Validity

Expert Evaluation Questionnaire #2

Please review the questionnaire and the items included and determine the relevance of each item and the response set. After doing so, indicate the relevance of the question with the corresponding numbered items listed below based on your knowledge of Military Families with Chronically Ill Children.

Question #1:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #2:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #3:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #4:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #5:

1. Not relevant
2. Unable to assess relevance without item.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #6:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #7:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #8:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #9:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #10:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #11:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #12:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #13:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #14:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #15:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #16:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question # 17:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #18:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #19:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #20:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #21:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #22:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Question #23:

1. Not relevant
2. Unable to assess relevance without item revision.
3. Relevant but needs minor alteration.
4. Very relevant and succinct.

Lynn, M.R. (1986). Determination of content validity. Nursing Research, 23 (6), 382-385.

Appendix D

Families Evaluation Questionnaire

Face Validity

University of Washington
School of Nursing
Department of Parent and Child Nursing

Dear Parents,

I am a graduate student at the University of Washington and presently enrolled in the Pediatric Nurse Practitioner program which places a focus on Children with Special Health Care Needs. As part of my Master's Project I am conducting a study concerning Military Families with Chronically Ill Children.

Purpose of the Study
I have designed a questionnaire **Military Families with Chronically Ill Children - A Needs Assessment Questionnaire** to explore the special needs of military families caring for a chronically ill child. Before distributing the survey to gather the information, I would like to ensure the questionnaire contains accurate information and addresses the areas of concern that are of importance to families such as your own. To do this I am asking families in which this questionnaire targets to review the questionnaire, provide suggestions, and give their input regarding any revisions.

Procedures
Enclosed you will find:

1) a **Military Families with Chronically Ill Children - A Needs Assessment Questionnaire**
2) a **Families' Evaluation Questionnaire**

If you are willing to participate, please take the time to complete both questionnaires. Before completing the Families' Evaluation Questionnaire, review and answer the questions in the Needs Assessment Questionnaire.

The information provided by you in completing the Needs Assessment Questionnaire will not be used in this study, but it is necessary for you to complete the Needs Assessment Questionnaire in order to determine the clarity of the questions and instructions.

When you are finished, place both questionnaires in the postage paid envelope attached and drop it in the mail. Completion and return of the questionnaire will serve as implied consent to participate.

Risks
There is little or no risk associated with this study. Participation or non-participation in this study will not affect your medical care, benefits or other entitlements. There are no costs or reimbursement for the study.

Voluntary Participation and Confidentiality

All questionnaires are anonymous and can in no way be linked to you. Please do not write your name or any information that might identify you. If you have any questions, please contact me at (206) 335 - 4156.

Again, thank-you for your cooperation!

Susan Morgan, RN

Families

Evaluation Questionnaire

1. Are the instructions easy to read and understandable?

   A. Yes

   B. No

   If you answered No, please write below why the instructions are not easy to read or understandable:

   _____

   _____

   _____

   _____

2. Are the questions easy to read and understandable?

   A. Yes

   B. No

   If you answered No, please write below the questions which were not understandable or easy to read and why:

   _____

   _____

   _____

   _____

3. Are there are any areas of concern to you and your family which have not been included in the questions?

   A. Yes

   B. No

   If you answered Yes, please indicate those areas which are of concern to you and your family and were not included:

   _____

   _____

   _____

   _____

4. Are there any questions which you believe are not important or do not apply to your family?

   A. Yes

   B. No

   If you answered Yes, please write those questions which you feel are unimportant or non-applicable and why:

   _____

   _____

   _____

   _____

5. Is the information included within each question accurate?

   A. Yes

   B. No

   If you answered No, please indicate which questions are inaccurate and why:

   _____

   _____

   _____

   _____

6. Are there any questions which include language or terms which are offensive?

   A. Yes

   B. No

   If you answered Yes, please indicate below which questions and the terms included you found offensive and why:

   _____

   _____

   _____

   _____

7. Are there any questions that contain jargon or terms which are unclear?

   A. Yes

   B. No

   If you answered Yes, please specify which questions contained unclear terms or jargon and include suggestions for revisions:

   _____

   _____

   _____

   _____

8. Is the questionnaire too lengthy or too short? In other words, would the length of the questionnaire interfere in your completing the questionnaire?

   A. Yes

   B. No

   If you answered Yes, please provide suggestions for revisions:

   _____

   _____

   _____

   _____

9. If you have any suggestions regarding improving or revising the questionnaire please write them below.

_____

_____

_____

_____

Appendix E

Expert Evaluation Questionnaire #1

Transcribed Responses

Summary of Comments
Experts
Expert Evaluation Questionnaire #1

Question #1, Question #2 and Question #3

Respondent circled (Yes) and added: On Questions #1 and #2 - maybe put in parentheses "(circle all that apply)".
Question #1 - maybe a choice re: special education/learning environment.
Question #3 - "Reason" - maybe more specific i.e.: "Reason for missing school" or "Reason for not attending school "(part of response "e").

Respondent circled (Yes) and added: Questions #1, #2, #3 are valid (content and face) and necessary for the study.

Question #4

Respondent circled both (Crisis) and (Adjustment) and added: Both phases, I cannot see being able to delineate each phase separately.

Question #5 and Question #6

Respondent circled both (B. Perceived needs) and (E. None of the above) and added: Appropriate support from any community.

Question #9

Respondent circled (Crisis) and (Normalcy) and added: Depends on how deployment is perceived by parent left behind.
Also circled (A). Unique stressors and added: Although fireman - i.e. wildfire - may experience similar episodes.

Question #10

Respondent circled (Adjustment) and (Normalcy) and added: Depends on perception.

Question #11

Respondent circled (Crisis) and added: Any move can be a crisis, depends on the type of illness and severity.

Question #16-22

Respondent circled (No) and added: How far away is your family support system? Some individuals live near sisters, parents, etc. What type of base are they stationed at; clinic, small hospital, medical center? How long have they been stationed there with a special needs child?

Respondent circled (Yes) and added: It would be interesting to know if the respondent is AD(active duty) or dependent (if the case) as I would feel the AD member may respond differently due to his/her frequent absences - ?guilty?

Respondent circled (No) and added: Add step (father or mother). How could the questionnaire ask "his/her/theirs" with tact. Many military have combination families.

General

Question #1

Respondent circled (No) and added: There is an underlying message that these parents did not get support. We do not know that. There are no questions that let them identify services that were or are available. All questions assume services were lacking. In this day of managed care it is also critical that the military community network with the civilian community and not duplicate services unnecessary. Does the military community lack the services because the civilian area has a strong similar resource?

Respondent circled (Yes) and added: Concerns re: how child's chronic illness affects AD(active duty) member's promotion eligibility/base/duty placement - how does that affect AD member's feelings towards his/her chronically ill child?

Respondent circled (Yes) and added: Yes. After a quick "read" of the Master's project proposal in my office the next soldier who [entered my office] was seeking marriage counseling or psychiatric help because his wife "did okay" when she was alone while he was unaccompanied [on] a 12 month Korea tour. The problems on the "reentry" paragraph [I] read aloud from [the] "proposed project" [to the soldier]. This opened dialogue, with the soldier agreeing.

Question #2

Respondent circle Yes and added: Any questions pertaining to available resources.

Respondent added C. Maybe, and stated: Maybe. Could questions determine age of child and length from diagnosis? The family's reaction to newborn with birth defects would not be the same as a seven year old with leukemia.

Question #3

Respondent circled No and added: See previous comments.

Respondent circled Yes and added: Excellent!

Question #4

Respondent circled No and added: Same comment as before. Circle all answers that are appropriate.

Question #5

Respondent circled Yes and added: Just need more comments about if they did get support.

Question #7

Respondent circle Yes and added: From reading this questionnaire I got the feeling that even if I thought I got appropriate support I had no where to indicate it. I think this questionnaire is important for gathering information but it does not appear neutral to me. Questions need to balance with items that allow the parent to identify the appropriate support systems that were available.

Respondent circled Yes and added: Excellent research!

Appendix F

Expert Evaluation Questionnaire #1

Key

Key for Evaluation Questionnaire #1

Question #	Phase	Research Question Answered
1		Definition
2		Definition
3		Definition
4	Crisis	Perceived Needs
5 & 6	Crisis	Perceived Needs
7 & 8	Crisis	Perceived Needs
9	Adjustment	Unique Stressors
10	Adjustment/Crisis	Perceived Needs/Unique Stressors
11	Adjustment/Crisis	Perceived Needs/Unique Stressors
12		Case Management/Perceived Needs/Adequate Support
13		Case Management/Perceived Needs
14		Case Management/Perceived Needs
15	Crisis/Adjustment	Perceived Needs/Case Management
16 -22		Demographics

Appendix G

Families Evaluation Questionnaire

Transcribed Responses

Summary of Comments
Families
Needs Assessment Questionnaire

Question #1

g. Currently in remission.

Question #3

Preschool age.

Is only 19 months.

Homeschooled.

Is not old enough.

Question #4

A handout that described the illness, treatments/medications used and the side effected of the medications and other illnesses that may be caused from the main illness.

Question #6

Information and education. My wife sometimes got mad because she didn't understand what was going on.

Less pressure from work because of lost time at work, or marginal performance because of stress.

Question #10

3 months to Saudi and 6 months to Okinawa were what made her sad. It was the length of the time the family was fragmented, the child's illness had nothing to do with it.

Financial support.

Question #11

Accessible housing available on arrival.

Question #12

Orthopedic doctors rotating in/out with drastically different approaches to our child's needs.

The "shoe/brace shop" at Madigan is very, very, very, very slow, inefficient, lack training and initiative. They took 2-3 weeks to cut a lift for one shoe and then said they didn't have the proper adhesive to attach it to the shoe. They could have used their Government Impact Visa card, local purchased Shoe Goo, and had the job done in 15 minutes. I ended up doing the job myself. Lunch Breaks, trips to the gym etc. were more important to the personnel there than customer satisfaction. In the USAF, the aircraft maintainers frequently work 12+ hours a day to support the mission. What's the Army Hospital Corps doing?

...Being forced to use Military providers.

Too much changeover in nursing staff. Child gets used to one nurse, and then they're gone. This makes the child start to refuse to get close/accept the caring feeling of the nurse. We had been treated at a civilian hospital with no real turn over. Big difference!

Question #13

Have ortho needs handled by Children's Hospital.

b. This was done for us. The old/new doctors are friends, this greatly helped us out emotionally.

Question #14

...dealing with Champus and Medicaid and who pays what.

What will happen when I retire or separate from the service. Will I be able to afford doctors/medications?

Permitting her to attend "sleep overs" at places where no one is experienced with her illness.

Question #23

Question #7 - both children have seizure disorders
Question #12 - Child has a continuity doctor who coordinates care.

We are very happy to report that our 19 month old son, although he suffered from a stroke at 32 hours, is developing normally. He walked at 10 months, and at 15 months had the language ability of a 20 month old. I would have to say the most

traumatic period of his life was the first 6 months. After that point, we began to notice that he was developing normally.

Our child is not ill, she has substantial developmental delays. We live about 15 miles from the military installation and do not feel at all connected to any support services offered at that location (if there are in fact any such supports offered). Our biggest needs relate to child care, particularly during TDYs, but other times also. This problem will only get worse, it seems, because childcare (generic) for a '12 year old' is just not available. The other issue is the lack of services available for our daughter as she gets older. The future looks very uninviting. Is she doomed to spend most of her adult life sitting with Mom watching TV because there is no funding available for day programs and no likelihood that these programs will ever become an entitlement?

1. When the sponsor is due to separate/retire have illness facts sheets provided to include:
   A. Medications required - possible generic or over the counter substitutes.
   B. Best places to buy medications.
   C. Recommended follow-up examination schedule.
2. Provide up-dates on research findings and sources to follow-up or keep informed of medical research (Nothing lengthy, just single page stuff.)
3. Provide handout booklets that describe:
   A. Illness
   B. Treatments
   C. Generic drugs/over-the-counter
   D. Latest research info
   E. Side effects of various treatment drugs
   F. Other related illnesses that may be triggered by original illness.

More help explaining situation to all supervisors in military member's chain to insure performance is not rated on situations relating to dependents medical problems or duty hours missed because of dependents problem.

It is my recommendation that each chronically ill child has a primary care provider that can coordinate all specialties' care and also be contacted by that specialist if there is any questions about other specialty procedures which are being provided right now.

Things have been great since our arrival at McChord AFB. Giving birth to a Downs Syndrome child in Germany was terrible. At that time, services such as fine and gross motor skills development was only available to school-age children. (I think this policy has since changed??) Which was crazy since early

development is needed. Information from a library on base was -0-. I sent to book clubs for information. Medical care was good. Born with a A/V canal defect we went TDY to Walter Reed for her heart operation. The military hospital care my child received at Landstuhl, Walter Reed and Madigan have been great. Very caring. For care in areas where expertise is needed such as a cardiologist she sees only one doctor. For everyday health care she sees many, but sometimes the input you get from other doctors is great.

Our child has hydrocephalus. We do not consider her chronically ill. We consider it for what it is, a birth defect. If we are to get future surveys and you want them filled out, please do not refer to children as chronically ill, it makes it sound like death.

Parents of chronically ill children know their child's condition, symptoms and emergency procedures better than any other doctor because we deal with it every day. Hospitals, doctors, nurses need to respect our experience and knowledge and not treat us like we know nothing.

We have received excellent assistance at all time. If necessary, we are still permitted to use her doctor's pager for personal assistance. We were given an immense amount of training as well. My daughter has a classmate who also is diabetic and has been for seven years. The school counselor has noticed that my daughter is more knowledgeable of her illness than her classmate. I attribute this solely to the care and training from the entire staff of Madigan Army Medical Center and the support of her doctor's previously diagnosed patients.